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ABSTRACT

Written for parents who have a severely handicapped child living at home, the booklet discusses problems, hardships, and rewards in the care of the child. Topics considered are acceptance, learning where to find assistance, family cooperation, sharing the caring, and ongoing adjustment. (MYS)

a handicapped child in your home

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This booklet is for parents who have a severely handicapped child at home, and it is about the problems, hardships, and rewards that they will find in caring for him. Millions of parents have faced this task, and in spite of the difficulties and burdens involved, they have done a courageous and positive job.

learning to accept

There are perhaps no words to describe the shock which parents feel when they learn for the first time that their child will be seriously handicapped. Sometimes, this crisis must be faced from the very moment of birth. For other parents, their child's handicap may not be noticed until later—when they can see that he is not making normal progress in sitting, walking, speaking, hearing, or developing self-care skills. And for still other parents, there is a tragic accident or illness which strikes a normal child and leaves him handicapped for life.

But however the difficult discovery comes, it is a turning point in the parents' lives, and it is like none they have faced before. Besides the terrible shock, they will also feel alone, depressed, and even guilty. "Why us?" and "Why our child?"

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foreword

We all know that not all children are blessed with normal physical and mental health. And that sometimes, through accident or illness, a child may be left with a serious health problem or a physical or mental handicap. But for each of the millions of handicapped children growing up in this country today, some individual family had to work out its own philosophy and plans to deal with this crisis when it struck in their own home.

In years past, parents were usually advised to put their severely handicapped children in special institutions, where they would be cut off from normal life. But now, we have learned that their own home—with their own family—is vastly better for the happiness and development of handicapped children than life in almost any institution.

But what effect can a handicapped child have on parents? On their other children? On their family life? What are the stresses, the pitfalls to be avoided, the hardships to be faced? And what are the rewards? Drawing on the experiences of parents who have faced a wide variety of problems, we hope to show that the handicapped child can broaden—rather than narrow—a family's opportunity for a richer, fuller life.

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Their first challenge is to face these painful reactions and to learn to accept them as normal. This is not an easy task. In fact, it is tempting to think about themselves—and how their family life has been affected—as little as possible. Devoting themselves to the extra needs of their child can leave them "too busy to think." And in the beginning, this is a natural way for them to deal with the problems of their child's well-being, and it is also a way for them to ease their own shock and distress.

But some parents will grow to learn that their own attitudes and philosophy are the real key to the future *total* health of their child —as well as their other children. They will spend time thinking about how they want their other children to feel about their brother's or sister's handicap. They will want their whole family to grow in love and wisdom as they face this special and often difficult situation. It is for this reason that many parents of handicapped children have said that a handicapped child in their home provided the richest experience of their lives and that it strengthened the values in their family life.

learning where to seek help

Fortunately, there are sources of counseling and assistance which can help parents through their early adjustment and assist them in getting started on a positive course of action.

- To satisfy their basic peace of mind about their child's condition, parents should seek the best possible medical advice

available to them. A diagnostic and evaluation clinic, for example, or a hearing and speech center or other special clinics may be available in their town or city. A public health nurse may be able to visit in their home from time to time. Information about assistance and guidance is usually available through the local department of welfare or department of public health.

- In addition to the advice of their own pediatrician and the local services described above, there are also many national organizations concerned with helping the handicapped. Already these include associations for muscular dystrophy, cerebral palsy, birth defects, mental retardation, epilepsy, diabetes, to name only a few. These organizations are an excellent source of information and guidance, news of research and treatment possibilities, good suggestions for physical therapy, recreation, education, and even the legal rights of the handicapped.

  The Bureau of Education for the Handicapped has compiled a list of every educational project in the United States which offers programs for handicapped children. Requests for information can be sent to "Closer Look," Box 1492, Washington, D. C. 20013.
- To adjust to their own needs and feelings, parents should not hesitate to seek guidance for themselves—as individuals and as parents. There was a time when the family minister was almost the only source of spiritual and psychological help for people facing such a crisis. Today he is still an invaluable support. But also today, more and more social agencies and community services have come to realize that "special"

children have "special" parents. They now offer not only practical guidance in the problems of caring for the handicapped child but also sensitive understanding of the emotional and psychological problems involved at home. Mental hygiene clinics, public health services, family service agencies, and many voluntary organizations welcome the opportunity to be of service.

- But perhaps most important of all, parents can learn from other parents who have experienced similar problems. There is probably no greater source of understanding, of sympathetic support, or wisdom. From the sharing of experiences can come practical assistance, emotional release, and genuine inspiration. Sometimes the new parents must make the effort themselves to seek out other parents; but many times, special parents in their community are already in touch with one another and will take positive action to include the newcomer in their bond.

  For example, the young mother of a two year old son with Down's Syndrome (mongolism), who lived in a small city in Iowa, remained isolated and depressed about her son's affliction. She felt very much alone with her problems and feelings. But, while visiting a nearby city, she was invited to a morning coffee hour which had been started by several young mothers for the purpose of having monthly discussions. After a lively visit with them, she exclaimed, "Why, this was actually fun—I didn't know you could *enjoy* talking about it!" When she returned to her home town, she investigated and learned that there were actually other parents of mongoloid children living there, and she sought them

out and began a discussion group. She reported that this activity made "all the difference in the world" in her outlook. When parents unite, in addition to the help they provide one another, they can also do a great deal to call the attention of their town or community to the needs of their handicapped children. Local parent groups, for example, have often stimulated better educational and recreational programs and have improved public interest and understanding.

In summary, the first important responsibility which the parents of a handicapped child must face is to deal with their own feelings about their child. This will require working, with patience, through the first shock and grief toward a constructive philosophy of accepting the challenge which has been given to them. They can overcome their feelings of isolation by welcoming—and even seeking—support, encouragement, and help from whatever sources are available to them. Their special child has indeed created special needs in them and also special problems. But like all parents, their main responsibility is still to create a well balanced and loving home in which *all* members of the family can grow and develop healthily.

from cope to cooperation

One very important and very practical consequence of having a handicapped child at home is that it is an additional drain on the family's time and energy. And especially on the mother's. For a special child requires extra time and effort—to help him to acquire self-care skills that will come slowly to him, or to do for him what he cannot do for himself.

This is an important time for the family to begin to learn to consider itself as a team, with a share of the responsibility assumed by each family member, however young. Even the handicapped child can have his own special tasks. And learning teamwork can be a very maturing experience for the other children. It can replace the "Do I have to?" reaction with an opportunity for them to feel that they are making an important contribution. The building of a spirit of teamwork can add greatly to the richness of family life, and there are only a few guidelines essential to its success.

- All members of the family should participate in planning the tasks. The distribution of family chores should be talked out by the whole family, with each child having his say. If this is not done, the parents, in making arbitrary decisions, might place too much responsibility on one or more of their other children—or at least, the child might see it that way and develop deep resentments. But if plans are made democratically, each child will learn the positive values of teamwork and can take pride in his own contribution. While planning for such teamwork adds to the parents' time demands, it is too important to be omitted, and it is the parents' responsibility to see that it gets done—at mealtimes, perhaps, or even at special family meetings for that purpose.

The use of teamwork should cover all of the tasks of family life and not just the added ones created by the presence of a handicapped member. It is an especially good way to build healthy relationships between all the younger members of the family. And it can

have particular importance in the relationship between the handicapped child and his brothers and sisters.

A teenage family member customarily took his younger spastic brother for walks to the corner grocery store. While he did this willingly, he became more and more embarrassed at the way passersby stared at his brother. When he confided his embarrassment to his mother, she advised him to walk closely beside his brother—placing his arm around him affectionately—whenever he was at the point of feeling embarrassed. When he followed her advice, he found that people smiled warmly at them and their stares of curiosity were replaced by looks of encouragement and approval. He grew less self-conscious and took real pleasure in providing companionship for his brother.

The brothers and sisters of a handicapped child who build a sensitive understanding of his needs and problems into their everyday relationship are gaining in maturity and wisdom. This can go a long way to offset any anxieties or embarrassments they may be sensing from the outside world.

- At the same time they are stressing teamwork, parents have an additional responsibility for seeing that each of their children is recognized not just as a team member but as an individual person. They should not assume that all aspects of their family relationships are fully satisfied by the teamwork approach to the challenge they are facing together. Each child in the family needs to feel recognized in his or her own right, and this important need may be overlooked if it is not very carefully

included by the parents in their own sense of priorities. Listening . . . sharing . . . supporting each child in his individual development—those activities should continue to be an important part of family life. And they should be viewed by the parents as a distinctly separate responsibility from that of building strengths in teamwork and cooperation.

- Parents must learn, too, to think about their own needs to get away for recreation and relaxation. This can help to relieve tensions that can sometimes cause resentment and irritability. It is usually the mother on whom the greatest emotional and physical burdens fall, no matter how effectively the family functions as a team. And *she* must learn to respect her own need for relief and to avoid feelings of guilt about leaving her child occasionally to pursue a hobby, a visit with friends, or other recreation. Unfortunately, most mothers today have developed the virtue of self-denial to near excess, and so this understanding calls for real maturity on her part. And it usually needs to be reinforced by firm promptings from other members of the family.

sharing the caring

In describing how a handicapped child had changed her perspective, one young mother remarked,

"Before I had Johnny I always thought of neighbors as just people next door to say hello to. One doesn't know what life is, just to go along taking everything for granted. It made me look at things differently. I have a better view of humanity.

People mean more to me now because when they're nice to Johnny, they're even more than a neighbor—they're a friend." And, another said,

"Our family is a better, more cooperative family because of Darleen. She has brought a blessing to this home, to me, to our other children, to our friends, and to our children's friends."

Most parents of handicapped children do come to feel such a deepening of values, which affects their relationships outside as well as within the home. People do care, and given the opportunity, they will find many spontaneous ways to demonstrate their friendship and concern.

The trends in family life today make this kind of sharing particularly important. Most families no longer have resident uncles, aunts, grandparents, or other relatives who enlarged the family group and enriched its life. Also, the time is long since past for a handicapped member to be kept isolated from the outside world. Sharing the caring—both inside and outside the home—is an important and natural result of values much needed today in family living.

The concern and support of friends and neighbors can give the family a great deal of lift and inspiration. It can also, in times of emergency, translate itself into practical assistance. When a parent becomes ill or has to be away on an emergency, someone may be needed to help with the care of the handicapped child. Parents should anticipate this need, if possible, by having in mind some friend, neighbor, or even voluntary service organization who could step in to help. If an emergency does arise, the volunteer helper

should be provided with a careful description of the child's schedule and his special needs for medicine or care.

A special mention should also be made of the gifts and contributions which can be provided by teenagers. One mother, in speaking of the relationship between her teenage daughter and her young handicapped son, said,

"Susan possesses rare gifts. She loves her little brother, and they seem to bring out the best in each other. She has her own life and interests too, of course, but she does things for him I could never do—I don't have the gifts of imagination and patience she has. She will be going to college in the fall and is now thinking of going into special education."

Even if there are no teenagers within the immediate family, many of them can still be found who are seeking out opportunities to serve—either individually or through community programs of all kinds.

Teenagers have a love of service and a sense of idealism which gives them great fulfillment from such work. They have a marvelous way with children, and especially with handicapped children—a no-nonsense, objective, lighthearted manner to which children respond with delight. At the same time, today's young people are showing unusual maturity in wanting to concern themselves with the problems of their fellow man; and the opportunity for service is a very rich experience for them. No special child could be luckier than to have such a friend, companion, or tutor.

the adjustment never ends

The handicapped child does indeed create many special problems and even hardships. These may change over time, but the challenge of adjusting to them and seeking solutions does not cease. As one mother said, "You *never* stop adjusting to it, but that's another way of saying you have to keep on growing."

As the handicapped child grows older, the parents will increasingly feel concern for his place in society and they will face practical problems about his future. These are serious matters indeed, for there will not always be satisfactory answers. But hopefully, during the early years of his childhood, they will have laid the foundations on which they will

construct their future decisions as wisely as they can.

There is comfort and strength tc be gained from the knowledge that millions of parents have faced these problems and have felt a rich inner growth brought about by such a unique opportunity for service. "Ed and I have both discovered a vast untapped store of strength we never dreamed we had," said one mother. "I mean spiritual strength. Ed has become more tolerant of people. He has mellowed. As for me, now I have a feeling of being an essential part of life."

Through patient and persistent effort to build a sound philosophy as a cornerstone for their family life and through seeking positive ways to share the needs with those who want to help, parents can realize rich, intangible rewards for themselves and all their family. And in this way, the special child can have a very large—and very special—family.

If there is a handicapped child in your home, here are some of the local organizations which may be able to give you information, counsel, or practical assistance:

Your church

Your department of health

Your department of schools

Your department of recreation

A diagnostic and evaluation clinic

A speech and hearing center

A birth defects center (Easter Seals)

Your local library

A family services agency

A voluntary agency such as FISH

A day care center for children with special needs

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